

Witness Name: Alastair Macrae

Statement No.: WITN000132001

Exhibits: None

Dated: 17/3/2019

INFECTED BLOOD INQUIRY

WRITTEN STATEMENT OF ALASTAIR MACRAE

I provide this statement in response to a request under Rule 9 of the Inquiry Rules 2006 dated 02 January 2019.

I, Alastair Macrae, will say as follows: -

Section 1. Introduction

1. My name is Alastair Macrae. My date of birth is the GRO-C 1972. I am a veterinary surgeon and work at the University of Edinburgh as a Professor of Farm Animal Health and Production. I intend to speak about my infection of Hepatitis C (HCV) by blood product Factor IX and blood transfusion. In particular, the nature of my illness, how the illness affected me, the treatment received and the impact it had on my life and the life of my family.
2. The dates I provide are an approximation of my treatment and infection. I have used trigger-points of my life such as my schooling, my University and my move to Newcastle and back to Edinburgh as reference points for all dates and times provided.

3. I can confirm that I have chosen not to be legally represented and that I am happy for the Inquiry team to assist me in writing my statement. The inquiry team has explained anonymity and I do not require it as such.

Section 2. How Infected

4. I was born in [GRO-C] and lived near [GRO-C] in [GRO-C] until I was eighteen years old. I was diagnosed with haemophilia B when I was six years old (1978). I lived with my family, none of whom had haemophilia. In our home we had bunk beds, and I came down on one of the bedposts and cut my lip/mouth area. I was brought to Ninewells Hospital in Dundee. I did not stop bleeding for three to four days, and was then diagnosed with haemophilia B (Christmas Disease). According to my mother, I was treated with my first blood transfusion at this time, and so I believe that this is the earliest possible date when I could have been infected with Hepatitis C.
5. I was in the care of Ninewells Hospital in Dundee until I moved to boarding school in Edinburgh in 1980, where I was put in the care of the Haemophilia Centre at the Royal Infirmary of Edinburgh. I was sent to boarding school in Edinburgh because of the reputation and proximity of the haemophilia centre. I was under the care of Professor Ludlam and other doctors in the Edinburgh Haemophilia Centre.
6. According to my mother, in the mid-1980s, the possibility that I was infected with HIV was raised with my parents. They were aware that I was to be tested for HIV, and my father and mother attended a consultation with Professor Chris Ludlam where the ramifications of HIV diagnosis were discussed. Prof Ludlam then went out of the room, returned with a sheet of paper with the blood test results, and he told them that the HIV result was negative. I was not present at this consultation, and was told about the HIV result by my parents afterwards.
7. In 1985 I was moved to a different boarding school in Edinburgh. My treatment for haemophilia at the time was on the basis of an "on-demand"

service. With on-demand service, I went into the hospital any time I had a need for Factor IX due to a bleed or bruise. Every time I was in hospital, the doctors would use it as an opportunity to perform blood tests and other checks on me. At the beginning in 1980 I would go every month for checks, then every couple of months. I also went to hospital every time I would have a bleed or bruise.

8. During one of these visits in the mid-1980s, the hospital offered me a vaccination for hepatitis A and B. They tested me for both, and I was diagnosed with both hepatitis A and B. There was no mention of Hepatitis C.
9. In the mid-1980s I moved to a six-monthly medical review, but also any time I was in the hospital they would run tests on my blood samples. When they were undertaking these tests, they checked my liver enzymes to ascertain if there was any liver damage. As my liver function tests continued to fluctuate up and down, the hospital said that there was a possibility I was infected with non-A non-B hepatitis. On reflection I understand this to mean Hepatitis C, but I accept that diagnoses was not readily available at the time.
10. In 1990 I went to the University of Edinburgh as a student, where and when I met my wife. In 1994 I went to the hospital for a six-monthly review. Doctor Janet Andrews was the first to inform me that Hepatitis C was potentially a problem. I gave informed consent to give a blood sample. A couple of weeks later I returned to the hospital, where it was stated I was positive for Hepatitis C. The doctor stated that there wasn't much information on the symptoms or treatment yet, but it could cause chronic liver conditions.
11. Hepatitis C did not give me any symptoms to the extent others have. I was never jaundiced; the only result I understood was that my liver had been damaged, although I had no symptoms. My liver enzymes would rise up and go down when I was tested. Other than that, the major symptoms I felt were as a result of my haemophilia.

12. When I was infected with Hepatitis C the doctors and nurses, not knowing much about the virus, were concerned that my then girlfriend (now wife) might become infected through me. I remember me being quite upset and deeply concerned about this. GRO-C

GRO-C

13. Guidance given on how to manage Hepatitis C was very vague. There was information on how not to spread it, such as the sharing of toothbrushes, dealing with drugs, having unprotected sex and sharing of razors. They were telling all they knew about Hepatitis C, as it was the early days of the infection.
14. The management of the Hepatitis C was good, or as good as it could have been at the time. They did not know much about what it did, other than it caused liver failure. The hospital undertook further tests to ascertain the extent of the Hepatitis C damage. I had a gastroscopy in 1994 to look for varicose veins in my stomach, and a liver biopsy. The gastroscopy revealed nothing abnormal, but the liver biopsy showed mild liver damage.
15. In late 1994, I was invited to participate on a clinical trial for the drug Interferon. The trial began in 1995 and lasted for six months. It involved a randomised clinical trial, with half of the participants taking higher doses/frequency of Interferon, and half taking a lower dose/frequency. I was in the high dose/frequency group and we were provided a syringe where we would inject ourselves in the skin just above our hip 3 times a week. We would go into hospital once a month for checks. I was told during the trial that the Hepatitis C could not be detected in my blood, and that the liver function tests were normal. There were always caveats, and never any guarantees about the progress being made. The doctors would say that the longer that they could not detect the Hepatitis C virus in my bloodstream, the more likely I was to be rid of it. I was told I was lucky to be in the higher dose group as the lower group stopped due to lack of progress. I learned that the other group began taking higher doses as a result of the success of the higher dose group.

16. The drugs gave me mild flu-like symptoms; headaches, aches, feeling drained and some nausea. I was warned about that at the start, and told that other patients stopped the trial because of the side effects. This was during the time of my University Final Examinations, so I was also very tired from long days of studying too. After the first month I adapted to it. The doctors offered, but I did not have to take any medicine such as paracetamol on top of it.
17. After that in 1995, I qualified as a vet and took my first job as a veterinary surgeon in Northumberland in Hexham. My care was transferred to the Royal Victoria Infirmary in Newcastle. Professor Peter Jones was the head of the Haemophilia Centre there.
18. Not much changed in my treatment of Hepatitis C, because the virus was not detectable in my bloodstream, and so no treatment was needed. GRO-C

GRO-C

19. Professor Peter Jones was a leading figure in the world of haemophilia treatment. He was also pioneering the use of self-administration of Factor IX treatment (called "home treatment"). My care changed around the 1996 point. They would give me Factor IX to bring home to leave in my fridge and inject myself. I was taught how to safely self-administer, as I was used to injecting animals as a practicing veterinary surgeon. This wasn't forced; it was given under the understanding that this is the future of my treatment. I also think that they were happy with me self-administering because I was a vet and I was therefore comfortable administering injections. With regard to Factor IX that I was to bring home, there was a lot of discussion regarding travelling, fridges and storage of medicines generally.

20. As part of the treatment I went to the hospital in Newcastle every six months for tests, among them tests for HIV and Hepatitis C. Test results would be given by Peter Jones or another doctor in the ward.
21. In October 1998, I transferred back to the Edinburgh Royal Infirmary when I began my PhD at the University of Edinburgh. By this point, Edinburgh had taken on board the self-administering treatment plan and continued to provide me with my own supply of Factor IX. The country was moving towards that direction. There were still those who attended the hospital for injections and there were still hospitals that self-administration had not been rolled out in yet. In 1999 or 2000, I had a big bleed at my family home in GRO-C and had to attend Ninewells Hospital, Dundee. It was still the old regime in that hospital and I had to wait for some time to be seen.
22. I would continue to have routine tests done on my blood every six months in Edinburgh for both HIV and Hepatitis C. On one occasion I tested positive for Hepatitis C. There was some concern as the strain was different to the Hepatitis C that I had. The hospital was concerned that there may have been a mix-up of samples in the lab and asked to retest me. The second test came up as negative, and they explained that there must have been a mistake with the lab testing process.
23. Since late 2000s I go once a year to test for Hepatitis C. I go either six-monthly or annually for tests. I understand that they no longer test for HIV. The hospital usually only contact me if there is something wrong in the results.
24. In terms of contaminated blood, vCJD was discussed in Edinburgh in the early 2000s. They said that some of the bloods could be infected with vCJD, and there was publicity that haemophiliacs could be infected with vCJD. The outcome was they would keep an eye on it, but conclusive tests were not available. As a vet I knew the infection well, as it is similar to BSE (mad cow disease). I understood how that blood could have been infected but I accepted that the risks were very small. I'm quite pragmatic about it.

25. I am now on recombinant Factor IX. Recombinant Factor IX is a synthetic replacement of blood-derived Factor IX meaning there is no risk of blood-borne infectious disease transmission. It was in the late 2000's where my regime was changed from blood derived Factor IX to recombinant Factor IX. It did not change the regime of attending hospitals one or twice a year. The rollout of recombinant Factor IX over the country was postcode dependent. Recombinant IX was not used in England as much or as early as in Scotland.

Section 3. Other Infections

26. I believe that the earliest that I could have been infected with Hepatitis C was in 1978 (although I could not prove this in a court of law, but this is the first time that I received a blood transfusion or plasma-derived clotting factor). I am not an intravenous drug user and I did not get it from sharing toothbrushes or any other method. I do not believe that I could have been infected otherwise.

Section 4. Consent

27. I believe I was tested for HIV without my consent. As I have previously stated in paragraph six, I was not involved in any of these discussions regarding HIV testing, and these recollections come from my mother. It did make me wonder how long they knew I was not infected without me knowing and why I was not told my blood was being tested.
28. For Hepatitis C testing, the doctors gave as much information as they had/could at all times. At the time I was offered a HIV test, and then subsequently told that it was negative, there seemed to be a lack of structure and organisation. The doctors probably hadn't taken into account

the repercussions on individuals by having a discussion about HIV. I also think you have to judge the care from the standards of the time.

29. I gave my consent to both clinical trials I participated in: one for the interferon and one for the Factor IX concentrate. In 1994 I went on a clinical trial for a purified version of Factor IX. It would have still been human derived Factor IX at that stage. They then took samples from the participants on an hourly basis, and then a six hourly basis. I was interested because Professor Ludlam was leading in haemophilia research and the trial could provide a significant assistance to haemophilia patients. A clinical trials laboratory in Livingston performing the clinical trial, and I was paid a couple of hundred pounds for me to take part. I was never told about the outcome.

Section 5. Impact

30. From my point of view and from my experience, haemophilia and Hepatitis C have not had a huge impact on my life. It doesn't affect my day-to-day interactions with people. I do not, on introducing myself, tell them that I have haemophilia and Hepatitis C. In job interviews I have had to state this however, GRO-C
GRO-C. I look well and I am well. I think I am luckier than most in my condition as I was treated in leading haemophilia centres such as Edinburgh, Newcastle and Dundee.
31. My family and first boarding school never stopped me from doing anything because I might get a bruise. If anything ever happened it was always a trip to the hospital to get some Factor IX. In the first school, they were very laid back about my haemophilia. I was just a child with a disease that required me to go to the hospital every week or so. In my second school, they were much more protective of my haemophilia, and the nurse in charge there wanted to wrap me in cotton wool. In this school, I always had to fight to play cricket, and they were worried that I would get bruised.

32. In University I was living with others who had illnesses too, such as a friend who had insulin-dependant diabetes. I never felt prejudiced or discriminated against because of my conditions.
33. GRO-C I always have to disclose at work that I have haemophilia and Hepatitis C. It would always remain in confidence with employers. On the effects of hepatitis A, B and C, I never really had many of the physical illnesses associated. I was never jaundiced or had serious liver failure. On the psychological impacts, my nature never allowed me to have any effects. The only time I was worried or deeply concerned was when the doctors informed me that my wife could have contracted Hepatitis C from me.
34. When it came to giving birth, GRO-C
GRO-C There were concerns that if we had daughters, if there was a stressful event such as the use of forceps, there could be bleeding. As a result, instead of going to the local hospital (Borders General Hospital) at birth, we might have to go to the Royal Infirmary in Edinburgh. However we have only had sons, and so this did not happen. We never told our family about these complications. It has not come up and it has not been necessary to say. GRO-C
GRO-C
35. Hepatitis C has not really affected my Mum and Dad. It was never really a discussion point. They knew about the hepatitis but have never been stressed about it. It has always been manageable for me, so they had no need to worry. Considering I was sent to boarding school in Edinburgh specifically for the purposes of ease of access to the haemophilia centre, it has been haemophilia that has affected my family more than hepatitis.
36. I received two types of treatments for my haemophilia: On-demand and in hospital service in Scotland, and later self-administering "home treatment" in Newcastle and Scotland. Self-administering is much better. I can treat bruises much quicker. When there are bleeds in the joints it may cause

arthritis in the future. If you are treated with Factor IX quickly after the bleed or bruise there is better long-term health outcome. In Scotland, the delivery of Recombinant Factor IX is subcontracted through BUPA. It's a prescription service that's delivered to my home when I require it.

37. I do not believe that there was a treatment that was available that I should have received. Interferon treatment left me with nausea and headaches for about a month. After about a month I adapted and was fine. The keyhole surgery where a liver biopsy was taken meant that I was kept in hospital overnight.
38. Generally speaking, my infected status has not affected how medical staff or dentists have treated me. Once, when I had a procedure in the Western General Hospital, it should have been a day surgery, but because of my haemophilia I had to stay overnight. Dentists know about my haemophilia and Hepatitis C and always ask about it.
39. I have not had any days off work due to the Hepatitis C infection. It hasn't affected my career in any significant way. As far as I am aware, it has had no effect on my education. I had three or four days off university for the liver biopsy, but no major impact.
40. The infection has had an adverse effect on me financially. Insurance cover and mortgages are the biggest issues for us. As a vet, the first advice we are given is to get income protection insurance. From 1995-1997 I was always refused on the basis of Hepatitis C. Other insurance companies refused on the basis of my haemophilia and Hepatitis C. Premiums for life insurance were always higher as a result of my infection. Travel insurance was always refused or at a high premium. When trying to get a mortgage in 1999, we were refused as a high risk for payment protection insurance.
41. At present I am fit and healthy. I am not on any prophylaxis. I am on "on-demand" treatment, and require fewer injections compared to when I was a teenager. Professor Ludlam would joke that I had reached "middle age

mediocrity", meaning I have become older and less accident-prone, and so required fewer haemophilia treatments.

Section 6. Treatment/Care/Support

42. I have never had any issues accessing treatment or support for my infection. I have always had good contacts and assistance. In some cases the hospitals were far ahead of their field. I never had to fight for anything. They doctors were always candid and upfront about the trials. In the interferon trial they warned me about the side effects, the nausea and headaches. They informed me that some patients had to leave the trial because of the effects of the medicine on them.
43. I did not receive and was not offered counselling or formal help with my conditions. My wife and I were offered counselling from the haemophilia geneticist around the time of my children's birth.
44. The inquiry investigators have explained that the British Red Cross (BRC) has provided a counselling service. They have explained that the BRC and the Infected Blood Inquiry are working together and that the Red Cross are aware of the circumstances of infected individuals. The BRC provide a contact point for people to discuss the issues and signpost them to local contact points. The investigators have provided a card with contact details and I will consider whether to make contact.

Section 7. Financial Assistance

45. I received two payments from the Skipton Fund in 2004 and 2016. I became aware of the fund either through the haemophilia centre in Edinburgh or through the Haemophilia Society (most probably through the haemophilia centre in Edinburgh). There were two one-off payments: I received the standard amount at stage one of £20,000 in October 2004, and £30,000 in December 2016.

46. Scottish Infected Blood Support Scheme sent a letter in December 2018 saying that future payments of £1,000 will be made annually. I think you get a base amount, and it is a sliding scale dependent on a number of factors. I do not receive winter fuel payments. The funds involved a lot of paperwork, and needed to be signed by the haemophilia centre. They filled it out and sent it on without problems.
47. It was an ex-gratia payment, we did know what that meant and understood the nature of the payment when we were signing it. We did not wish to sue the government or any other institution, so this was not a concern for us.
48. I have had a fairly minimal effect of the Hepatitis C, I have been quite fortunate in that way. I have never been significantly challenged.

Section 8. Other Issues

49. There is a wide variation of how people have been infected or affected. For the situation and circumstances of my infection, I have received good medical care and funding. The outcome and funding received has been commensurate to the mistake and infection being made. Mistakes have been made and in my circumstances, the best treatment available was given. I'm grateful for the money received from the Skipton Fund. I would regard myself as being at the minor end of the scale on how Hepatitis C has affected me.

Statement of Truth

I believe that the facts stated in this witness statement are true.

Signed GRO-C

Dated 17/3/2019